

People with Parkinson's find that their ability to communicate with other people is often limited by the effects of their Parkinson's upon their speech, writing and non-verbal communication skills such as facial expression and body language. The loss of these communication skills can have a profound effect on the quality of life of the person with Parkinson's as well as that of their family. Communication difficulties can also create a misleading impression of the person to other people, so that they are incorrectly seen as being difficult, deaf, drunk or unintelligent. Misunderstandings arise due to lack of awareness of these difficulties and many people with Parkinson's feel very socially isolated as a consequence.

Speech

About half of all people with Parkinson's have associated speech problems at the onset of their condition. As Parkinson's progresses, so too do their communication difficulties. Often the severity of their speech difficulties is related to the extent of their physical difficulties, but not always.

Speech can be:

- slurred
- monotonous with lack of variation and expression in the voice
- hoarse and tremulous
- lacking or fading in volume
- disordered in rate and rhythm. There can be hesitancy or difficulty in getting the voice started - speech may also get progressively faster
- unintelligible
- and responses may be very slow

As a result of all these factors, people with Parkinson's may find that they are not readily understood by other people. Talking in a crowd, over noise or daily communicative activities, such as using the phone, may be impossible. This further isolates them and their family, and is often a cause of great worry for families, as they fear leaving people with Parkinson's on their own who cannot communicate well.

Problems with speech may also convey the incorrect impression that the person is demented, depressed, apathetic, or unfriendly.

It is also recognised that people with Parkinson's have extreme difficulty with the following in a conversation:

- turn taking
- following a multiple topic conversation
- interjecting

As a result they resort to a minimal returns option such as "uh huh".

This coupled with impoverished facial expression further heightens the impression that people with Parkinson's are dull, not understanding what is being said or bored.

The lack of ability to rapidly produce spontaneous expressions of speech, linked to facial gesturing, also compromises their ability to command a conversation. Many people with Parkinson's find that the person they are talking to takes up the conversation by repeating what they have just said, leaving the person with Parkinson's sidelined.

People with Parkinson's can also have difficulty understanding shorthand forms of speech, such as "Coffee?" when offering someone a drink, and

the more subtle nuances of speech such as sarcasm. This together with their often slow response can increase the misleading impression that they are stupid.¹

Social withdrawal by the person with Parkinson's and their families can be common. Communication and relationships within families may also be compromised. The interaction with professionals may also be affected. Studies reveal that times with professionals may be shorter, because of the poor interaction of communication. Professionals often misunderstand the slow responses and poor conversation skills and label them as uncooperative and even unlikely to attend clinics. All based on poor verbal and non-verbal abilities.

Non-verbal communication

Spontaneous and controlled facial expression together with body language form a very important part of communication. Unfortunately, immobility (due to muscle rigidity and slowness of movement) deprives some people who have Parkinson's of this form of expression. As a result subtle communication can be impossible. Misunderstandings can arise and assumptions made that people with Parkinson's are unresponsive, bored, or unintelligent.

Research has also shown the negative effect that reduced facial expression has on the impression formed by health professionals of people with Parkinson's compared with people with ischaemic heart disease. People with Parkinson's were thought to be more anxious, hostile, suspicious, unhappy, bored and tense than those with cardiac disease. They also came across as less intelligent, more introverted and passive.²

¹ **Scott S., Caird F.I., Williams B.O.,** (1985) Communication in Parkinson's Disease, *Chapman Hall*. (Out of print, but should be available via a public library).

Scott S., (1997) The importance of communication, European Parkinson's Disease Association Parkinson magazine, Issue 9.

² **Pentland B., Pitcairn T.K., Gray J.M. and Riddle W.J.R.** (1987), The effects of reduced expression in Parkinson's disease on impression formation by health professionals, *Clinical Rehabilitation*, 1, 307-313.

The main problems people with Parkinson's can experience with facial expression include:

- lack of spontaneity
- lack of facial expression which belies intellect
- impassive appearance because of difficulty with frowning and smiling
- when looking in the mirror, it is hard to recognise one's features
- inappropriate responses which are misinterpreted

In addition there can be a lack of body language and non-verbal cues, such as smiling or nodding, due to the typical features of Parkinson's such as bradykinesia (slowness of movement), rigidity (stiffness), and tremor (shaking). The person may have an air of general stillness with a reduction of body and hand gestures. Head and neck movements may also be restricted. Initiating movement can be difficult and this can become increasingly slow and clumsy. Conversely some people experience abnormal involuntary movements (dyskinesias) as a side effect of anti-Parkinsonian drug therapy. This can affect any part of the body including face and mouth and as a result, people with Parkinson's may be unable to control their movements sufficiently to speak and communicate.

The need to rely on the patience of a listener while people try to get their message across is frustrating and very depressing.

Often communication centres around needs, such as going to bed, the toilet or needing a drink, all social conversation stops. Often the ability to express one's personality or sense of humour is severely affected by the loss of verbal and non-verbal skills and make the person with Parkinson's depressed.

Writing

Many people with Parkinson's complain of problems with handwriting caused by tremor and

Pentland B., (1991), Body Language in Parkinson's Disease, *Behavioural Neurology*, 4, 181-187.

lack of co-ordination. Handwriting difficulties can be one of the first symptoms of Parkinson's and can include:

- starts off normally and becomes smaller and smaller (micrographia)
- can be very spidery and difficult to read
- illegibility or difficulty in writing due to shaking of the hands, rigidity, and difficulty controlling small sequenced movements

See the PDS information sheet *Handwriting (FS23)*.

Other Issues

One of the most misunderstood aspects of Parkinson's is the "on-off syndrome", i.e. the fluctuations in ability resulting as a side effect of levodopa drug therapy. With the "on-off syndrome", a person can change from reasonable mobility to absolute immobility, sometimes in a few minutes. Some people have likened this to the idea of a light being switched "on" or "off". "Off" when there is no response to the drugs and "on" when the drugs are effective. Speech and body language can also be affected, so that a person's ability to communicate may also fluctuate. For instance, the voice may be louder and more intelligible when the person is "on" but be quiet and difficult to understand when the person is "off". If this is not understood, confusion and misunderstanding can result, with the person being labelled lazy or difficult when in fact they are not. Often people do not understand that even when off the person still understands.

One lady and gentleman demonstrated this beautifully, while out she asked him what time it was. She got no response and realised that he was "off". Some time later he turned to her and said, "It was 3.15 when you asked me". This inability to respond at will is frustrating and often misconstrued by those around them.

See the PDS information sheet, *Motor Fluctuations (FS73)* for more details on the on-off syndrome.

What can be done to help these problems?

Levodopa drugs used to treat Parkinson's can help increase volume in speech. Speech and language therapy is also recommended and early referral is advised, as further improvements are possible. The speech and language therapist's assessment enables them to determine the difficulties that a person is having and how these affect their quality of life. With the person with Parkinson's they can then work together to overcome these difficulties. The speech and language therapist will also advise on alternative communication methods if these are indicated. Speech and language therapy may be carried out at home, as intensive group therapy, or as an outpatient in a day hospital. Carers can also get advice from a speech and language therapist.

Carers are extremely resilient when faced with impoverished facial expression and poor conversational skills. They adopt excellent coping strategies which include "jumping in" to respond. This can be misunderstood by professionals, who interpret it as "not allowing their person with Parkinson's to speak for themselves", when often it is a strategy to give their loved one time to take on board the topic and time to respond.

Under the Royal College of Speech and Language Therapists "Communicating Quality" guidelines, all speech and language therapy should be available through self-referral to the local hospital or health board. Remember not all speech and language therapists are specialists in Parkinson's, so ask to see one that has experience in treating Parkinson's. Obtaining speech and language therapy through self-referral can sometimes be difficult and where this occurs, people should contact the doctor, Parkinson's Disease Nurse (if they have one) or the PDS for further advice. See the PDS information sheet *Speech and Language Therapy (FS7)*.

Some local PDS branches have also developed links with speech and language therapists who have a special interest in Parkinson's. A speech and language therapist may give talks at the branch meetings and sometimes they will run speech and language groups in association with

the branch. The local PDS Area Manager or Development Worker can provide more details.

Research³ highlights the additional benefits if speech and language therapists often work with physiotherapists and occupational therapists to provide a more “multidisciplinary” approach to care. Physiotherapists can help with mobility and posture problems. Occupational therapists can help with particular physical aspects of communication, such as problems to do with writing.

See the PDS information sheet *Physiotherapy (FS42)* and the PDS leaflet *Occupational Therapy and Parkinson's (B47)*.

A final note

Remember that communication is a two-way process. It is vital that we do not give up trying to communicate with people with Parkinson's, even though there may be a lack of response.

Parkinson's Disease Society Resources

PDS publications and resources can be obtained from the PDS distribution agent:

Sharward Services, Westerfield Business Centre,
Main Road, Westerfield, Ipswich, Suffolk, IP6
9AB. Telephone: 01473 212115.
Fax: 01473 212114.
Email: services@sharward.co.uk

All cheques in payment for PDS Resources should be made payable to PDS Sales Ltd.

Information sheet code: FS6

Updated version: May 2003

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All PDS information sheets are reviewed on a yearly basis in January and updated as soon as relevant new information becomes available.

³ See Ward, C.D, Rehabilitation in Parkinson's disease and parkinsonism, in Parkinson's Disease and Parkinsonism in the Elderly, Meara J. and Koller W.C (eds), 2000, Cambridge University Press, 165-184, ISBN: 0 521 62884 9